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ABSTRACT

This paper describes the first year of a 5-year study which, when completed, will identify the needs and concerns of disabled consumers from virtually all categories of functional limitations and all walks of life. The participants will include men and women between the ages of 18 and 65 from a variety of socioeconomic and geographical backgrounds. In the first year of the study, data were collected at 12 focus group sessions involving individuals in 4 functional limitation categories: blindness, low vision, upper extremity motor impairments, and lower extremity motor impairments. Categories of need that emerged throughout the focus groups were safety/health, privacy, independence, convenience, and employability. Two areas of concern not directly related to technological needs also emerged: attitudes and money. The paper concludes that: (1) the single most often identified need is for a better understanding by the general population of the needs of people with disabilities; (2) many focus group participants did not see new technology as the answer to their problems; and (3) access to computers is key to increased independence, employment potential, and increased convenience. A moderator's guide for use with the focus groups is appended. (JDD)

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CONSUMER NEEDS ASSESSMENT

A QUALITATIVE STUDY OF THE NEEDS OF PEOPLE WITH DISABILITIES

CONSUMER NEEDS ASSESSMENT PROJECT YEAR 1

RESULTS OF THE FIRST YEAR OF A FIVE YEAR STUDY

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August, 1989

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INTRODUCTION

Over 32.5 million Americans - 14.1 percent - have a chronic health condition that limits them to one extent or another in their daily activities. For 7.6 million of these individuals, the disabling condition is so severe that they require assistance with activities of daily living (ADL), such as getting ready in the morning, preparing and eating meals, or getting around.[1]

The extent to which a disabling condition limits one's activities is affected by many factors, not the least of which is the availability of adaptive equipment or devices to accomplish a particular task. Furthermore, the way in which one defines "adaptive equipment" is dependent to a great extent upon the perspective from which it is viewed. In order to eat a steak, for example, modern societal norms have decreed that silverware - a sharp knife and a fork, in this case - are necessary to cut the meat into bite-size pieces. For someone with limited hand function, a knife with a curved handle might be required to provide the leverage necessary to cut the steak. Both the "regular" knife and the curved-handled knife are adaptive equipment in one sense of the term. The major difference between the two is the greater availability of the "regular" knife due to the fact that most members of society at large require such equipment in order to cut their food.

The proliferation of relatively sophisticated home electronic equipment over the past ten years has altered dramatically the way in which many individuals utilize their time and complete necessary tasks in their daily lives. Microwave ovens are used in many homes in lieu of stove tops for cooking vegetables or heating up leftovers, as well as for more sophisticated cooking ventures. Remote controls enable one to operate electronic equipment from across the room. These kinds of conveniences are used and appreciated by many segments of society; for someone with a disability, however, devices that afford convenience to most may serve as important tools toward increasing and maintaining independence.

People who are limited in their daily activities as a result of a disabling condition in some instances require - or could use - specially adapted equipment that was designed for the specific purpose of accommodating a disability within the context of everyday living. A wheelchair, for example, provides a means of mobility to someone who is unable to walk, whereas a white cane provides assistance in mobility to someone who is blind. Both are "mobility aids," but the nature of the assistance that they provide the individuals is determined by the nature of the disabling condition, so there is no direct relationship between the two types of devices other than the fact that they aid in mobility.

As part of the Electronic Industries Foundation Rehabilitation Engineering Center's (EIF/REC) mandate to assess the needs of consumers with disabilities, the REC began a project in 1988 to obtain qualitative data on the needs of disabled consumers, as expressed by consumers themselves. The specific purpose of the project was to determine the adaptive equipment, or technological needs of this population, using input from disabled consumers as the major source of information.

From the outset of the project, several tenets have been observed. First, the research team agreed that the methodology needed to be as open-ended as was

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[1] Data on Disability from the National Health Interview Survey 1983-1985, National Institute on Disability and Rehabilitation Research, 1988.

possible, within the limits of established research practice, in order to allow the issues of what consumer needs are to emerge from the research subjects themselves rather than from the researcher's pre-conceived assumptions of those needs. Secondly, there has been a recognition throughout the project that the needs of people with disabilities will vary depending upon the nature and extent of the disabling condition. As mentioned previously, both people who are blind and those who have lower limb impairments may require an adaptive device in order to get around, but the kinds of mobility aids that they require are completely dissimilar. It is essential, therefore, that any research on the needs of "the disabled" recognize and account for the vast differences in needs that may be identified by various segments of the population that are identified as "disabled."

A third factor that has governed the conduct of this study is the recognition that adaptation to daily living involves not only specially-adapted equipment, but also devices available to the mass market. Just as microwave ovens and remote controls for electronic equipment can provide greater independence to people with and without disabilities, so can telephones, televisions, computers, and alarm clocks. In our study of the use of these devices by people with disabilities, we concentrated our attention not only upon the use of the devices themselves, but also upon the design features that affected usage by people with disabilities.

No device will allow for increased independence or ease of function if one cannot afford it, and so another focus of the research has been to examine the methods by which people with disabilities obtained the equipment or devices that they needed. Whereas some subjects in the project have achieved a fairly high level of personal independence due to access to expensive equipment, others have remained relatively dependent upon others for assistance and/or have been unable to participate in employment because of the lack of funds to purchase necessary equipment.

The basic ideas and tenets described above served as the foundation upon which this project was developed. Specifically, it was designed as a five-year project to obtain qualitative information about the needs of people with different kinds of disabilities. Each year the needs of four functional limitation categories will be examined through the use of focus groups until, at the end of the fourth year of the study, a total of sixteen functional limitation categories will have been the subject of research. The fifth year of the study will be used to coalesce and analyze the data being obtained in years one through four.

A concurrent project was planned to take place in conjunction with the qualitative focus group study. That project was to have been a quantitative assessment of the needs of people with disabilities, using the results of a large, nationally circulated questionnaire. However, the REC has been unable to locate funding to support the development and/or acquisition of a database of disabled consumers from which to draw a statistically-verifiable sample of disabled consumers. In the absence of such a database, the survey assessment of needs has been postponed indefinitely.

This report is based upon the focus group sessions conducted during the first year of data collection (see Methodology). Consequently, it is not possible at this time to predict the conclusions that will emerge at the end of the five years of research. Interim conclusions are being presented, however, based upon the specific needs and concerns that were identified by the Year One participants.

METHODOLOGY

Qualitative Research - Rationale

A qualitative research approach utilizing focus group input was selected for this study for several reasons. First, one of the goals of the project was to explore the specific needs and concerns of disabled persons in greater detail than could be obtained through traditional quantitative methods. For this reason, a decision was made that each focus group would concentrate upon a specific category of functional limitation rather than attempt to identify needs of all disability categories through heterogeneous groupings.

A second reason for selecting qualitative research over quantitative research is to identify some of the subjective elements in a decision-making process. In this case the decision-making process was that regarding the purchase and/or use of adaptive equipment by the disabled participants.

The third major reason for the choice of qualitative research on this topic was to generate ideas within the context of a modified open-ended discussion format as one of the major project goals. Disabled participants were to identify what their personal concerns were, and then were to share their suggestions for new products or improvements to existing products that had emerged out of their own individual experiences with living with a disability.

Researchers recognize that it is inappropriate to generalize about a given population based upon the responses obtained from focus group participants. Qualitative research cannot be used as a substitute for quantitative research. However, qualitative research is an accepted tool to use when little quantitative data exists in a specific research area, and in fact can enhance or expand upon quantitative findings at times.

Study Design

This is a five-year study which, when completed, will identify the needs and concerns of disabled consumers across the country from virtually all categories of functional limitation and all walks of life. The participants will include men and women between the ages of 18 and 65 from a variety of socioeconomic and geographical backgrounds.

In traditional qualitative research studies, focus group participants are selected at random in order to achieve a cross-section of the general population. Because the populations included in this study are so small and fragmented across the country, it would not have been feasible to develop focus groups using conventional random selection methods. Consequently, a decision was made to identify a variety of professionals in diverse locations and professional settings across the country (i.e. in rehabilitation centers, vocational rehabilitation programs, training programs, and similar programs) to assist the study team in identifying potential participants. By utilizing different resources in each site, a wide cross-section of disabled individuals was reached, although it is important to note that all of the participants were affiliated in some manner with an established program rather than being truly random selections from the community at large.

Three focus groups were convened for each functional limitation category included in the study. An attempt was made to conduct the research across the widest possible variation of demographic characteristics in order to maximize the randomness of the sample. To achieve this objective, sessions were held in three different geographical locations for each disability category, with sites varying from year to year.

The functional limitation categories examined during the first year were: blindness; low vision; upper extremity motor impairments; and lower extremity motor impairments. During subsequent years, additional functional limitation categories will be examined in order to obtain a wide range of disability categories over the five-year course of the project.

Each focus group consisted of 8 - 12 adults from 18 - 65 years of age. Participants were selected by the local organizer, who was asked to try to locate a cross-section of disabled individuals, including members of both sexes, employed and unemployed individuals, and people from varying socioeconomic backgrounds.

The focus group sessions were strictly limited to 1-1/2 hours each. After a general introduction to the focus group concept and the specific goals of this study, each participant identified him/herself and provided information about the nature of their disability. Following that information, the moderator asked a series of open-ended questions about daily function and activity, based upon the format outlined in Appendix A.

The information obtained during the focus group sessions has been organized and analyzed to reflect the needs expressed by specific functional impairments. If geographically-specific needs were identified, those exceptions were noted in the analysis of the data.

DATA ANALYSIS - YEAR ONE

Introduction

Twelve focus group sessions were held during Year One of the study, with three groups in each of the following functional limitation categories - blindness, low vision, upper extremity motor impairment, and lower extremity motor impairment. One session for each of the four functional limitation categories was held in the following locations - large West Coast urban area, mid-size East Coast urban area, and small Midwestern city.

In order to ensure a wide range of participants, a variety of local resources were used to contact the focus group participants, including a rehabilitation engineering center, public and private rehabilitation and training centers, vocational rehabilitation programs, and a local advocacy program.

As indicated in the Moderator's Guide (Appendix A), the focus group discussions were organized around the concept of "going through a typical day," excluding the part of the day where the individuals were at work or school. The purpose of using this format was to concentrate upon technologies used in daily life rather than upon employment-related technology. The second major topic addressed was out-of-town travel. If time permitted, employment-related technology was discussed at this point in the sessions. The final fifteen minutes of all sessions, however, were devoted to obtaining the answers to the following two questions:

1. What technology do you depend upon the most in your daily life?

2. I wish that "they" would come up with (fill in the blank).

S.P.I.C.E.

In the analysis to follow, the reader will notice that the information obtained through the focus group sessions is organized categorically rather than chronologically according to the format followed in the sessions. This method of analysis was selected because it seemed to be the most appropriate way to summarize the ideas that kept emerging throughout the sessions, regardless of disability, place of residence, or station in life.

Briefly, the categories of need that continued to emerge throughout the first year of the study can be summarized succinctly:

- Safety/Health
- Privacy
- Independence
- Convenience
- Employability

Virtually every problem/need/technology identified during the twelve sessions held during this first year of the study could be categorized in one or more of the categories identified above. Safety and health concerns were paramount, and ranged from the need to address the health needs of people with multiple disabilities (blindness along with diabetes, for example) to the need for better methods of assisting blind people at busy traffic intersections.

Privacy issues also were stressed by the focus group participants, especially among blind subjects and those with low vision. The dependence upon others to read personal mail or to handle financial information was cited repeatedly as an issue that needed to be addressed.

A third major area of concern was independence. For individuals with limited or no use of upper extremities, that concern often manifested itself around the topic of getting ready in the morning; for those with blindness or low vision it often had to do with getting access to printed information, such as instructions to operate appliances, or reading newspaper ads or catalogs for information on new products. For all groups in Year One, transportation was a major concern within the area of independence.

A fourth general category under which many concerns were expressed was convenience. One participant emphasized that, at the end of the day, she felt as if she had been through the equivalent of two days of living because of all of the extra effort required just to get through the day when blind. Whereas "convenience" may at first glance sound trivial in comparison to a concern such as safety, the level of disability-related stress added on to all other stresses of daily living cannot be ignored, as shall be seen in the following analysis.

Finally, the last major category of concerns addressed by the focus group participants were those related to employment. Although the format of the focus group discussions purposely avoided employment-related technology in order to focus upon daily living issues, virtually every focus group MADE employment an issue, so much so that ignoring it in this analysis would have made the report incomplete. For many of the focus group participants, employment was the most important area in which technology could be made available and/or improved.

Attitudes and Money - Two Concerns

There were two areas not directly related to technological needs that emerged in every session, and therefore merit mention. The first was awareness of the needs of people with disabilities by those who are not currently disabled; the second was that of funding to purchase needed equipment. Although each focus group was informed that the topic of discussion was to be centered around technology and devices that could make life with a disability easier, many of the problems that emerged under all five categories - Safety/Health, Privacy, Independence, Convenience, and Employability - existed or were made worse by insensitivity or carelessness on the part of others, rather than because of a lack of adaptive technology. Technology can only go so far to make a crosswalk safe for a blind pedestrian; if a careless driver enters the intersection without looking either with or against the light, there are few "technological" solutions to protect this pedestrian. Similarly, no matter how much adaptive equipment is available, no job on the second or third floor of a building with steps only is going to be accessible to a potential employee in a wheelchair. Nor is getting a job any easier if the potential employer does not understand, or is afraid of disability.

It was necessary in all of the focus group sessions to remind the participants that the topic of discussion was technology. However, in fairness to all of the participants in this study, it cannot be emphasized strongly enough the importance placed upon attitudes toward people with disabilities, and the need to increase the awareness of the population at large on how to avoid causing additional problems through ignorance or insensitivity.

The other general topic that emerged was funding for technology. Many of the "wish list" items that appear in the upcoming sections are devices that already exist and are presumed to be "available" to people with disabilities. If an individual does not have access to funding, however, it is as if the device does not exist for that person. Consequently, perhaps it is not so much a matter of developing more devices as it is ensuring that existing devices end up in the hands of those who need them.

BLINDNESS/LOW VISION

Introduction

A total of six focus groups were held with people who either were blind or legally blind. Three groups were conducted with completely blind individuals. One group consisted primarily of individuals who had been blind for many years (most since birth) and who for the most part were employed. A second group included students or former students in a training program as well as two instructors of blind pupils; in this group, several participants had recently

become blind through illness or injury, while others had been blind since birth or childhood. One group had a wide range of individuals - employed and unemployed, early and late-onset blindness, and educational backgrounds ranging from high school through college. All six groups had an approximately equal number of males and females.

The composition of the groups with legal blindness was similar to those with total blindness, since the low vision groups were held in the same locations as the previous ones. However, more of the low vision participants had late onset vision problems due to disease (glaucoma, retinitis pigmentosa and macular degeneration were the three primary causes of vision loss in these groups) than was the case in the groups with total blindness.

Problem Areas

Safety/Health

Two major safety/health issues were raised in the blindness/low vision groups. The first issue was that of traffic and crossing the street safely. Several participants felt that crosswalks should be marked more carefully, preferably through a change in texture of the pavement inside the crosswalk or through raised lines indicating the location of crosswalks. Other participants commented that this approach was used in some localities already; this particular group concurred with the suggestions in general.

A second problem identified was knowing when one should proceed to walk across the street. Someone mentioned that lights at certain intersections emit a "tweet-tweet" signal, and the consensus was that this concept should be expanded.

The major safety problem identified with respect to being a pedestrian was inconsiderate and unsafe drivers who either ignored or didn't see pedestrians in the crosswalks. This was seen as a serious - even life threatening - problem by many of the participants with no identifiable solution other than to "make people more aware" of the presence of blind pedestrians.

A second safety issue identified was concurrent medical conditions and the problems therein that are compounded by blindness. Several participants were blind as a result of diabetes. Thus, they had medications to take and had to control their diets carefully. Furthermore, one individual mentioned that the diabetes had decreased the sensitivity of her extremities, so she had a reduced capacity to feel things as well. This could create problems such as unknowingly burning herself around the house or elsewhere. Those on restricted diets were limited in their ability to read food product labels to determine whether or not there were inappropriate ingredients in prepared foods. One woman who is allergic to Nutrasweet related an incident where she had asked a clerk in a grocery store to get her a pack of Pepsi that was on sale. "If I get just a gulp of Nutrasweet it's off to the hospital," she said, yet the clerk accidentally had given her a six-pack of Diet Pepsi. "It was only because someone came over and happened to see" that she had been given the wrong kind that a potential mishap had been avoided. Sorting and measuring medications proved a problem for some, particularly if medications inadvertently were moved from their assigned places.

Many of the focus group participants who are legally blind have limited sight, but proper lighting is necessary in order for them to use their sight. Thus, a suggestion that emerged in one of the low vision groups was to improve safety outside the home by having lighting systems that are activated by the presence of a person or animal. A second suggestion was to have a lighted keyhole to enable the individual with poor sight to see where the key should go.

Privacy

Privacy was cited by many participants in all three of the focus groups with blind individuals as a serious concern. Personal, handwritten letters (or typed letters, if one did not have access to a reading machine) could not be accessed unless a third party read them to the blind individual. Concern also was expressed at the intrusion of privacy caused by dependence upon others to read bank statements or other financial documents.

"It's not that your reader or your friends are going to go out and blab about your personal business," said one participant, but just the idea that "at least on many issues, you've some privacy."

The privacy issue appeared to be of particular concern to single people and married couples in which both partners were blind.

Independence

> "Whether it's getting up in the morning,...shopping or whatever,...because of the lack of sight, we need help. It's not that we're dependent, you know - 'leeches on society' - but there's certain things that you need sight for to function, and because we don't have it we need help. So if anything could be developed technologically that would be like an electronic eye...that would give you access to visual stimuli whether it would be printed material, colors....All of us can get to the store...but once we get there, no matter how independent we are getting there...once we get inside we need someone with a pair of eyes to help us."

The participants in the focus groups were for the most part extremely independent people who either worked or attended school, lived alone or with a (sighted or non-sighted) spouse, and accomplished as much as possible in their daily lives without assistance.

In their own homes, most expressed the feeling that they were in control of their environment and essentially independent of the need for outside assistance. Most had developed systems to identify what clothes went with what (although identifying spots was a problem). Women who wore make-up had developed routines that seemed to work for them. When new compact discs or records were added to a personal collection, standard procedure seemed to be to put Braille labels on the new additions, according to group participants. Appliances also were brailled to indicate where the controls were located. And, meticulous house-and record-keeping ensured that the people who participated in the focus groups, at least, were able to control and manipulate their home environments with relative ease.

Once the person with impaired sight steps into the outside world, however, the situation was perceived as being completely different, because that part of the world was designed for sighted people. Transportation by city bus was possible,

for example, but only if the blind individual can ask the bus driver or a bystander for assistance in locating the appropriate bus. Once on the bus, he/she needs assistance in knowing when to get off. Exchanging paper money for goods and services is dependent upon the honesty of the person with whom one is doing business. Shopping for groceries is complicated by the inability to see what is on the shelves, what has been advertised in the newspapers, and the prices of items in the store. Hotels and other buildings become mazes to negotiate when floor levels on elevators are marked with flat panels rather than raised numbers (or braille), suite numbers are painted on doors, and door lock systems consist of cards to be inserted and removed "when the light comes on."

The greatest aids to independence, according to the focus group participants were:

Personal

- Talking alarm clocks
- Remote controls for sound systems and televisions
- Reading devices - Optacon, Kurzweil reader, talking computer (for those who had access to such devices)
- Tape recorders, talking books/record players, radio, television shopping services
- Guide dogs or canes
- Sighted spouse

General

- Tactile maps when available
- Braille elevator controls
- Braille directions to operate appliances
- Toll-free numbers
- Banking by phone
- Audible street signals

Many suggestions emerged when the groups were asked to identify "wish lists" or items they would like to see invented or become more readily available. At the top of that list in all six groups was a hand-held reading device (and, since it was on a "wish list," most participants added the hope that such a device could be readily affordable.) Other suggestions included:

- Something to read the bar code on products to identify the product and determine the price
- Something to read street names from a distance

° Talking appliances

° A money identifier under $20

° A radar-operated or programmable car

° An audible digital display reader

Convenience

Most of the "independence issues" raised in the focus groups address in one sense or another, the issue of convenience, as well. For every task or activity that requires the assistance of another person, the burden of seeking that assistance and using it to accomplish the task rests with the individual who has the disability. Consequently, a "one-step task" automatically extends to at least two steps, and a three-step task becomes at least a four-step process, and so forth. Several participants in the focus groups emphasized this difficulty, and noted its importance in terms of completing everything that was necessary to be completed in a given day.

The low vision participants faced another problem that was accentuated by the fact that they had some sight remaining. Many legally blind people do not "look" blind, and therefore are harassed by sighted people for carrying white canes ("Don't you know those are for blind people?") or for asking what a clearly-marked sign says ("What's wrong? Are you blind?!"). Thus, in addition to having to figure out how to compensate for the lack of sight in a situation, they also must contend on a fairly predictable basis with rudeness and ignorance on the part of people that they approach for assistance.

Employment

Employment was not originally intended to be a topic of consideration for this study, as the purpose of the project was to examine the needs of disabled individuals in day-to-day life. However, participants continued to mention employment issues as a major concern. All three groups emphasized two factors. First, attitudes of potential employers were seen as a source of problems for blind individuals seeking employment. The second issue mentioned in all groups was computers. Many of the participants who were employed use computers regularly in their jobs; those who are not working see access to computers and the skills necessary to use them as important requisites to employment.

MOTOR IMPAIRMENTS

Introduction

Six focus group sessions were held with individuals who had motor impairments. The great majority of these participants had spinal cord injuries, although the groups also contained several individuals with spinal cord dysfunction due to disease or other injuries. Four of the six groups included both male and female participants; two groups had male participants only. Three of the groups were composed of individuals with both upper and lower extremity impairments; the remaining three groups consisted of individuals with lower extremity impairments only.

Problem Areas

Safety/Health

Safety and health issues were not raised by the motor impairment groups to the extent that they were by the blindness and low vision groups. The one health issue that was raised in one of the six groups related to the use of functional electrical stimulation to improve body strength. One of the participants said he had been involved with a program "that makes you pedal a bike. The reason that I got involved with it is that I hoped it would give me a cardiovascular workout which I can't get any other way because of the small amount of muscles I have." He described a long, cumbersome process of getting ready for the workout, and summarized, "It just wasn't worth it. Another friend of mine tried it (too) and we just decided that we don't want to spend all day, toning up muscles that we don't use anyway."

One participant expressed an interest in a system that would give him good wrist function, as long as such a system could be implanted and stimulated by remote control rather than with wires.

Privacy

Again, privacy issues were not raised by the motor impairment groups to the extent that they were raised by the blind and low vision groups. The major exception to this rule regarded the need for an attendant by most of the people with upper extremity involvement; however, this issue was raised within the context of independence issues rather than privacy, per se.

Independence

Independence was by far the major concern addressed by all six motor impairment groups, and it was particularly stressed by those with upper extremity involvement. From getting up in the morning, to preparing and eating meals, bathing, dressing and getting around, virtually all of the participants with upper extremity impairments required assistance. Most hired attendants to assist them; others relied upon able-bodied spouses.

Some participants had been disabled 25 years or more and seem to have developed methods or attitudes for coping with life as it was dealt them. Said one, "I'm one of the old timers, and we had to overcome more difficulty than these guys now because...when we came in there were a lot of crazy rules that we had to overcome. They believed that because we were handicapped we didn't have brains ...like outcasts...."

Other participants had not been injured long, and were quite forceful in their expressions of distaste for life as they must now live it: "I hate being a quad." "This is hard to deal with." "I can't do the things I want to."

Most of the participants who are dependent upon attendants did not see any way that technology could take the place of attendant care. One man with lower extremity involvement only felt that a better shower chair would be helpful. Other participants described the equipment that they use in their homes, including adapted closets (with low hanging rods), a lift to assist one into and out of the bathtub, and extensive architectural alterations to accommodate wheelchairs in the home. For those with upper extremity involvement, however, continued dependence upon attendant care was seen as a necessary evil.

Other aspects of day-to-day living could be made easier through the use of technology, however. Reaching devices (poles with a "pincher" on the end to grasp objects out of reach), cordless telephones, multiple telephones, and remote controls were seen as essential tools to everyday living, as were reliable mobility aids such as wheelchairs.

All of the groups spent a considerable amount of time discussing wheelchairs and seating systems, as these are the devices used most regularly by mobility-impaired people to achieve independence. Many participants felt that the first chair prescribed for them immediately after they became disabled was inappropriate to their needs. Several people with quadriplegia but some hand function easily maneuver lightweight manual wheelchairs (Quickie, Quickie II or Quadra), yet initially were prescribed powered wheelchairs by their therapists. Others who were prescribed manual chairs felt that the chairs they initially were prescribed were too heavy and/or unattractive for their needs.

Of those who were prescribed powered wheelchairs and felt that they needed that kind of a wheelchair, there generally was satisfaction with the wheelchair itself, regardless of the age or manufacturer of the chair. One individual claimed to have problems with the circuit box on his Invacare Rolls wheelchair.

Others expressed a preference for the Everest & Jennings control boxes over the Invacare controls because of size and placement of the controls. However, the same groups expressed a belief that the electrical system itself - the wiring - on the Invacare chair was superior to that of the Everest & Jennings chair.

The vast majority of participants use simple foam cushions for seating rather than some of the more sophisticated systems available, primarily because of the cost of such systems.

Other independence issues discussed by the motor impairment groups related primarily to attempts to get around outside the home and participate in selected activities. As with the blindness and low vision groups, the perception was that the problems that a person with a disability faces generally are not in the home, where most have made adaptations to address their personal needs. The problems occur when one goes out.

Major problems identified consistently by the focus groups on motor impairment include:

- Getting into buildings - stairs
- Shopping - reaching objects that are beyond reach
- Narrow aisles
- Traveling by plane, especially if there is no ramp to the plane (someone must carry you) or if one uses a battery-operated chair (although gel cell batteries are both legal and safe, some pilots still do not allow them because of ignorance). Several participants also told "horror stories" of wheelchairs being damaged irreparably during shipment.
- "Accessible" toilet stalls that do not have enough room to allow you to shut the door

- Counters that are too high
- Double doors where one gets stuck between the two sets of doors

In summary, most of the "technology" that the mobility-impaired participants recommended consisted of:

- Improvements to, and better prescription of, wheelchairs
- Technology to improve accessibility through better design and implementation of accessibility guidelines
- Better awareness of the needs of disabled people by those who come into contact with them (airline personnel, clerks in stores, or people on the street)

Convenience

ONE convenience issue dominated virtually every focus group discussion, and this issue was handicapped parking. Although most public parking lots now have designated handicapped parking places, the following problems were noted:

- Unauthorized people park in them
- Other cars park too close to the disabled person's car/van, making getting in and out impossible
- Some handicapped parking spaces are too narrow
- Sometimes the parking space does not provide access to the ramp up the curb

While many of these problems appear unsolvable until people's awareness of the needs of the disabled driver improves, one concrete suggestion did emerge. One participant suggested developing a mechanical "arm" that could be raised on the driver's door (or door to a van ramp) that extends out as far as is needed for the disabled individual to enter the vehicle. This would prevent other drivers from parking too close to the disabled person's car or van.

Other convenience issues that arose were concerned primarily with recreation. On the "wish list" of items to be invented or become more readily available were a fishing pole holder, handles to enable a disabled person to get into/out of a fishing boat, accessible hiking trails, and appliances that open from the side (oven, dishwasher).

Employment

Employment problems centered primarily around potential employers' attitudes; there was a general feeling among the groups that the necessary technology to adapt workplaces was there for almost any kind of work, as long as the employer was willing to work with a disabled employee. "Hire us first; we'll figure out some way to get the job done," said one participant. As with the blind/low vision groups, computers were seen as an important tool to aid in employment, as well.

CONCLUSIONS

It would be premature at this point to make conclusions about the needs of disabled people in general, since the first year of the study has focused only upon people with blindness, low vision, upper extremity impairment, and lower extremity impairment. In addition, it would be incorrect to generalize about the needs of the disabled population at large based upon a limited qualitative research effort. However, several patterns have emerged that are worth mentioning.

First, the single need that has been identified most often to date is for a better understanding of the needs of people with disabilities, by those who currently do not have a disabling condition. Improved understanding of the difference between total blindness and low vision, for example, or the need for leaving enough room for a wheelchair user to enter a car, would reduce many of the unnecessary barriers that people with disabilities face every day.

A second major fact that emerged is that many of the focus group participants did not see new technology or new "gadgets" as the answer to their problems. Instead, many of them would simply like to have the means to afford technology that already exists.

A third factor that emerged is the awareness of people with diverse needs of the importance of the computer to them. Although blindness and spinal cord injury are as different as two disabilities can be, it is evident that the computer can contribute to increased independence, employment potential, and increased convenience for all. Consequently, attention should be given to maintaining and improving the concept of universal accessibility to such technology.

APPENDIX A

MODERATOR'S GUIDE

CONSUMER NEEDS ASSESSMENT PROJECT - DISABILITY GROUPS

Introductory Remarks - Will be talking about how a disability affects everyday life, and what kinds of products or devices could ease those difficulties.

I. Introduce each participant - Name, how long disabled, and what do they find most difficult about being disabled.

II. Going through a "typical" day, but skip going to/from work, being at work or school

a. Process of getting up in the morning

b. Getting ready

c. Kitchen - probe for use of electrical appliances

(Some groups digressed at this point to discuss other issues - please include those "side discussions")

d. Relaxing at home - probe for use of controls to TV's, compact disc players, etc.

III. Activities outside the home - BANKING (important with blind groups), sporting events, concerts, movies, etc.

IV. Long distance travel - hotels, motels, airports, airplanes

V. Upper/lower extremity dysfunction groups - probe for mobility equipment (wheelchairs, functional electrical simulation)

VI. Current device, equipment they "couldn't get along without"

VII. "Wish list" for new devices that would make their lives easier

VIII. False close (formally close session but informally continue discussion)